



National
Kidney
Foundation™

30 E. 33rd Street
New York, NY 10016

Tel 212.889.2210
Fax 212.689.9261
www.kidney.org

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Karen B. DeSalvo, MD, MPH, MSc
National Coordinator for Health Information Technology
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Suite 729-D
Washington, D.C. 20201

RE: Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap

Dear Dr. DeSalvo,

The National Kidney Foundation (NKF) appreciates the opportunity to comment on this roadmap for nationwide interoperability of health information technology (HIT). NKF is America's largest and oldest health organization dedicated to the awareness, prevention, and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of people at risk. In addition, NKF has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI). In response to the request for prioritization of use cases NKF recommends that status of care transitions (3), population health data available at the community level (5), and electronic access to laboratory results (41) be the first areas where technical standards, policies, and implementation specifications are developed.

The status of transitions of care should be available to sending and receiving providers to enable effective transitions and closure of all referral loops (3).

The National Quality Strategy (NQS) identifies six priorities, including promoting

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effective communication, coordination of care, and patient safety. Coordination of care across practice settings through the use of information technology would be a major step forward in improving patient outcomes for those with complex chronic conditions, like chronic kidney disease (CKD). The ability for patient's healthcare teams to know the status of their patients, the care they receive, and the medications they are prescribed in other healthcare settings will help improve patient outcomes and lower health care costs by delivering on the promise of the right care at the right time – avoiding hospitalizations, readmissions, medical errors and duplication of services. This is particularly important for improving care people with CKD. Health information exchange among a CKD patient's health care practitioners is critical for ensuring that patient safety, particularly during transitions of care and in closing referral loops. Patient safety interventions such as avoidance of certain medications like non-steroidal anti-inflammatory drugs (NSAIDs), avoidance of contrast-induced media, and medication dose adjustments reduce patient's risk of acute kidney injury, progression of CKD, and permanent kidney failure.

If CKD progresses to later stages it is important for primary care practitioners (PCP) and nephrologists to collaborate to improve care. Improved interoperability of medical records should facilitate improvements in communication. Delayed or late referral to a nephrologist is a major problem associated with the management of CKD patients. It results in higher mortality and increased length of stay in the hospital.¹ Late nephrology referral misses opportunities to initiate treatment aimed at slowing kidney disease progression and reducing cardiovascular risk. Further, the absence of adequate preparation and planning with a nephrologist results in emergent dialysis starts. In 2012, over 40,500 CKD patients, 41% of the population starting dialysis, were not previously referred to a nephrologist, resulting in as many as 12 days of excess hospitalization per patient.^{1,2}

As previously noted, the transition from advanced kidney failure to dialysis is a particularly vulnerable time for people living with kidney disease. Gaps in

¹ Chan MR, Dall AT, Fletcher KE, Lu N, Trivedi H. Outcomes in patients with chronic kidney disease referred late to nephrologists: a meta-analysis. *Am J Med.* Dec 2007;120(12):1063-1070.

² United States Renal Data System. 2014 Annual Data Report: Epidemiology of Kidney Disease in the United States. Bethesda: National Institute of Diabetes and Digestive and Kidney Diseases. National Institutes of Health;2014.

employment, hospitalization and death are common immediately before and after dialysis is started.² Fragmentation of the health system contributes to poor communication between the health care professionals who care for the patient before dialysis initiation and the dialysis clinic staff. Improved electronic health information sharing should help to promote care coordination and overcome fragmentation during this vulnerable transition.

Additionally lack of communication between dialysis facilities and hospitals is a missed opportunity to reduce readmissions and improve medication reconciliation in the transition between the dialysis clinic and hospital setting. Dialysis patients are hospitalized, on average, nearly twice a year for an average of 11 hospital days. In 2012, nearly 40% of dialysis patient discharges from all-cause hospitalization were followed by an unplanned readmission within 30 days.³ Sharing health information is key to care coordination and patient safety, particularly discharge summaries, which include information about hospital diagnosis, antibiotic use, blood stream infections, red-blood cell transfusions, and modifications in dialysis prescription. Yet, there is little electronic information exchange from acute hospitals to dialysis clinics. Interoperability standards would create greater ease of information sharing.

Population health measurement is supported at the community level and includes data from all relevant sources on each patient in the population and is accessible to providers and other stakeholders focused on improving health (5).

Over 26 million people have CKD, yet only 10% are aware they have it⁴ and another 73 million are at risk. Risk factors for kidney disease include diabetes, hypertension, age over 60 and a family history of kidney failure. A recent study published by researchers leading the Centers for Disease Control and Prevention's (CDC) CKD surveillance program shows that the burden of CKD is increasing and that over half of U.S. adults age 30-64 are likely to develop CKD.⁵ Intervention at the earliest stage is vital to improving outcomes, lowering health care costs, and improving patient

³ Ibid.

⁴ Tuot DS, Plantinga LC, Hsu CY, et al. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. Clin J Am Soc Nephrol. Aug 2011;6(8):1838-1844.

⁵ Hoeger, Thomas, et al. The Future Burden of CKD in the United States: A Simulation Model for the CDC CKD Initiative, Am J Kidney Dis. 2015;65(3):403-411.

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experience. Unfortunately, in a recent clinical study, only 12% of primary care clinicians were properly diagnosing CKD in their patients with diabetes – who are at the highest risk of kidney disease. Earlier PCP diagnosis and treatment of CKD, and improved collaboration with nephrologists⁶ should help close the gaps in appropriate care.

Diagnosis by the ICD-9-CM code is associated with patient awareness (of CKD) leading to improved opportunities for patient engagement⁷ – a key component of the National Quality Strategy and Healthy People 2020. Discussions and surveys of patients with kidney disease have shown that those with kidney failure would have welcomed the opportunity to modify their lifestyle had they understood they had kidney disease and known its risks. Easy access and aggregation of health data for population health queries would have a tremendous impact on early CKD diagnosis. Because CKD can be identified through blood and urine tests (urine albumin to creatinine ratio and a serum creatinine to estimate kidney function), many patients with declining kidney function have laboratory data in their medical records documenting this decline. Unfortunately, most electronic health records do not have registry function for query generation.

Registry function for laboratory data across health systems would allow for improvements in diagnosis of early CKD. In addition, this data will allow for better estimates of the burden of kidney disease nationally and locally, providing opportunities for quality improvement activities and health services research across practitioners, payers, and community health organizations.

Providers and patients receive electronic laboratory results from laboratory information systems (LISs) inside and outside their organization (41)

Given the low rates of diagnosis of CKD by PCPs, allowing access to laboratory data should allow patients to seek information about their kidney health. Making laboratory results directly available to patients should allow patients to initiate the

⁶ Szczech LA, et al. Primary Care Detection of Chronic Kidney Disease in Adults with Type-2 Diabetes: The ADD-CKD Study (Awareness, Detection and Drug Therapy in Type 2 Diabetes and Chronic Kidney Disease), PLOS One November 26, 2014.

⁷ Ibid.

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diagnostic process by proactively seeking out medical advice from practitioners and educational information from governmental and community health organizations.

Given the gap in diagnosis and awareness of CKD, providing people living with CKD access to their laboratory data empowers them to be proactive to protect their kidney health – a choice that is often currently unavailable. CKD patients with access to their lab data can monitor their disease progression, seek out dietary advice, and make lifestyle changes to improve prognosis and outcomes.

Lastly, PCPs access to their own clinical laboratory, diagnosis and treatment profiling will pose opportunities for individual clinician practice improvement and systemic quality improvement activities.

While our prioritization of use reflects the benefits to CKD patients, NKF believes the same prioritization will benefit many other patients with chronic diseases. We appreciate ONC's consideration of these comments.

Sincerely,

Joseph Vassalotti
Joseph Vassalotti, MD
Chief Medical Officer